7-3-2019

Susan Huff Oral History.

Biography

Ms. Susan Huff, RN, MSN, is a leader and administrator in palliative, hospice and home care, with an emphasis on developing healthcare programs for children with complex illness and their families. Her nursing career began in pediatric oncology and pain management; she started the first pediatric Pain Management service at the Women and Children's Hospital in Buffalo New York in 1989.

During this time, she developed the Essential Care Program; one of the first Pediatric Palliative Care Programs in the United States. She began working on a national level to change hospice care for children and to develop Palliative Care Programs across the United States through program development and government advocacy. Ms. Huff chaired the NYS Palliative Care Coalition and the National Hospice and Palliative Care Advisory Council for Children for several years. Currently, she oversees an organization that provides comprehensive care for children at home and in the community in Maryland and the District of Columbia. This organization provides home health, infusion pharmacy, home medical equipment and respiratory services. In addition, Ms. Huff consults for Johns Hopkins International and is currently working on projects in China.

Ms. Huff credits children and their families as her greatest teachers, driving her interest in the development of programs to assure families have both access and choices in care.

Interview Abstract

Ms. Susan Huff begins by identifying some of her experiences during the earliest practices of hospice in the U.S., including her work in developing a multidisciplinary team model that could provide a service to follow a patient through end of life. Ms. Huff also describes some of her work closing the provider education gaps around hospice philosophy, pain management, and communication.

Ms. Huff then describes her work bridging pediatric palliative and pain management programs. Ms. Huff also describes her role in many programs and projects that successfully demonstrated that her model of pediatric palliative and hospice care met the desires of patients and parents while working within the confines of limited funding.

Ms. Huff concludes the interview with her vision of furthering research on outcomes to empower programs to deliver the "seamless choices in care and access" that parents and patients deserve.

Glossary of Acronyms

Abbreviation	*Definition*
CEO	Chief Executive Officer
CMS	Centers of Medicare and Medicaid Services
ELNEC	End of Life Nursing Educational Consortium
ICU	Intensive Care Unit
IV	Intravenous therapy
MS-Contin	Morphine Sulfate Controlled Release
NHPCO	National Hospice and Palliative Care Organization
NICU	Neonatal Intensive Care Unit
PACC	Program of All-Inclusive Care for Children
TPM	Topiramate
VNA	Visiting Nurse Agencies

Interview Roadmap

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****Edited for grammar and content by Ms. Huff.****

[00:00:00]

***Bryan Sisk**:* Today is July 3, 2019. I am Bryan Sisk and I'm in St. Louis, Missouri interviewing Susan Huff over the telephone for the Pediatric Palliative Care Oral History Project. Ms. Huff is in Baltimore, Maryland. Thank you, Ms. Huff, for joining me today. To get us started, could you just tell me when your mind turned toward pediatric palliative care as a career focus?

Susan Huff: As a career focus. Probably about 1990.

***Bryan Sisk**:* Can you trace it to a particular moment or experience or was it just a gradual awareness?

Susan Huff: Well, my original interest started because I was a pediatric oncology nurse working at that time at Roswell Park Cancer Institute in Buffalo, New York. We had a pediatric and a separate adolescent unit, which was the first adolescent unit in the country, I believe. At that time, were seeing patients from all over the world. There were no pediatric hospices at that time. In the early 80s it came into the United States. I started there in '82 and around '87, '88 is when I became involved on a peripheral way, in developing a palliative care program that was different than hospice with a group at the hospital. My interest stemmed from my experiences as a pediatric oncology nurse and my interest in pain management.

I started working in pain management in the late 80s and was working, at that time, not only at Roswell, but with the New York State Association. We formed a hospice and pain association in New York State that had focus on education, physician, and nurse education, but primarily physician education on pain management. Understanding and learning at that time about what hospice was as a philosophy and my experience as a nurse and having parents that I cared for, not wanting to come back in the hospital, or patients that were from other countries wanting to be with their loved ones and all the work that we did in trying to get families back together at end stage. My experience between death of children as it happened in the hospital, and witnessing death of children at home, even without a formal home care or hospice program lead me to believe there has to be a better way for patients and families to die in the place they choose.

As an example at that time, because there were no structured programs outside of the hospital setting, we had a family that didn't want to come back in. I would say to my attending, "Give me an order for morphine and I'm going to just go after my 3:00 to 11:00 shift to the home and I'm going to hookup an IV [intravenous therapy]." So, I would actually put a nail in a mantle because there were no portable IV poles that could be brought anywhere, and hookup pain medication to help at end stage for patients and families. At that time, most oncology patients had a central line placed called a —broviac catheter. So, it was really convenient and helpful because we were still able to give the same type IV pain infusion that we did in the hospital, at home. Then a couple of my nurse colleagues started doing it with me. Sometimes the physicians would make visits to the home. These experiences at home were in great contrast to experiences in the hospital where families would call and say, "I'm noticing something different in my child. I'm bringing them in," and they would die in the car on the way to the hospital. I can vividly recall David, a 3 yr old patient, standing at the nurses station, we would see them walking down the hallway. Dad ws carrying David in his arms, and I said to the attending or the fellow, "Oh, my God. The baby's dead already." Then obviously there were many experiences of children dying in the hospital setting. We did BMT on our unit as well, so there were a good deal of deaths in the hospital. Some expected and some not expected.

So, those experiences led up to me and about two or three colleagues to look outside of what existed for care at home. We had a small grant at that time from a community organization in Buffalo, New York. We ended up doing surveys with parents. We did a couple hundred parents of patients that had cancer and had died in the hospital. What they wanted was very different than what hospice was offering at that time. That led to the development of a model that was originally embraced in 1988 by Hospice of Buffalo. It was started by a nurse, a bereavement counselor, and a child life specialist. They started doing education at that time with Buffalo hospice on the difference between the needs of children and adults, particularly differences in age appropriate needs including he pain management. Through the first year when it was under Buffalo Hospice, it was a disaster because they would be admitted, and everybody would agree that the patient wanted to die at home. Then the hospice would say, "Oh, but that TPN has to be discontinued before they leave." "No, no, there's no way we're giving IV morphine or Dilaudid, or any of those things." You got to have everything—and nothing fit. We recognized way back then the needs for children and their families were totally different than adults.

So, the program was closed at Buffalo Hospice and the team, took the program the Children's and Woman’s Hospital in Buffalo and in conjunction with—Roswell Park Cancer Institute a program was developed. We started a program in the Children's Hospital and they had access to a home health company for children, which was the VNA [Visiting Nurse Agencies]. The Program was named Essential Care, named by parents who had already had the benefit of taking

their child home to die with nurses from the hospital. (no formal program, just through doctors writing orders for meds given at home)

Over the years, between '87, which is when we had our first patient die at home, to I think '89, '90, the program Essential Care was started. The program used three disciplines, child life, bereavement, and a pediatric nurse. Little by little, using the home health benefit a few patients came on service. The parents and families were very satisfied with the care and service at home. The challenge was nursing was the only discipline reimbursed through home health. There had to be fundraising for the bereavement piece and child life. Child life specialists had never been used before outside of a hospital setting, however we felt it was an integral part of what was needed for the patient and siblings because of our experiences with cancer patients and child life specialists in the hospital. Invaluable service, in the hospital—you couldn't do without them.

During this time, my full time job was on the pain service at Roswell Park Cancer Institute and while Essential Care was developing it's patient base in home Care, I was seeing these same patients for pain management. This lead to me doing consultation for pain at home, and also I ended up backing up the Essential Care Nurses when they went on vacation or were sick. During this time Anne Armstrong Dailey was developing hospice care. We sent our team to Children's Hospice International, met Ann Armstrong-Dailey in the late 80s and did some hospice training there. I was working on a pain management service at Roswell and seeing adults and pediatric patients. We realized hospice was growing in interest but we still felt the homecare model with the multidisciplinary care was working. our service kept growing from oncology referrals to infant referrals, to neurodegenerative disease, to pulmonary disease to prenatal hospice services.

Eventually, I left Roswell Park and was hired at the Children's Hospital in Buffalo, this was 1990, to start a pain management service there. My full time shifted to develop a pediatric pain service with Anesthesia and Nursing at The woman and Children's Hospital of Buffalo but I was still doing consults in the home. I worked in the nursing division and with the department of anesthesia and setup an entire nurse education program and a format with anesthesia for doing post-operative pain, worked with sickle cell patients and oncology patients. We also did chronic pain management. At that same time, I was doing all the consulting in the home. It was very satisfying and intriguing to me that home is really where the families wanted their patients to be. We were very successful from the standpoint of family satisfaction and the evidence in when you had children that were in the hospital for long periods of time, and then you got them home, even though they might have been at death's door in the hospital; you got them home and they lived for a month afterwards because they were comfortable and happy and in their own environment. So my heart really started to lean towards care at home.

At the same time in the early 90s, the nurse that had specifically started the Essential Care program moved to Texas. I took her place as a clinical coordinator and then the service continued to grow. We started with the oncology population because that's who we knew. I mean I had very good relationships with the oncologists and the hematologists because they were seeing all the same patients. We moved into the ICU [intensive care unit] to the NICU [neonatal intensive care unit] arena. We ended up recruiting physicians to be our physician champions. All of this was being done under a home health benefit with raising money to support the non-billable services. We knew it was the right model, but it was not reimbursed appropriately. As we started to grow, a couple things were happening in the community. I was working more and more with Ann Armstrong-Dailey and Children's Hospice International at trying to look at why we have the gaps in models. Should I continue?

[00:11:14]

***Bryan Sisk**:* No, please. This is great.

Susan Huff: So, I started looking at why we have these models and what would be needed to change the system. My ultimate goal was to really create a whole new model, not have a hospice benefit and a home care benefit, but to have—and I still believe a benefit from birth all the way through that doesn't designate which is which, is ideal. The hospital was having a very—as we were growing and getting bigger, and by that I mean instead of two or three patients on census, there were 15 to 20 patients on census, we had part-time staff. The way that we did this was, between the full-time nurses that were hired at the home care company, we had part-time staff from the child life department and the bereavement department. We were kind of utilizing all the different cost centers—kind of the way that it's still done now in a lot of places; you rob Peter to pay Paul and you bring them all together—even though everybody's paying somebody's salary out of other different cost centers.

At the same time, hospice was changing for adults. At that time in the early 90s, Hospice of Buffalo had a very innovative CEO who created an organization called The Center for Hospice and Palliative Care. That's when they started to think, 'We can't continue to take care of patients the last 24 hours of their death in adults. We have to start to look at how we can improve their quality of life upstream.' So, this hospice in Buffalo purchased a home health organization and they were expanding. The hospital ended up wanting to sell Essential Care, which was under the

Children's Hospital of Buffalo, and develop a relationship with the Center for Hospice and Palliative Care so that they didn't have the financial burden. When all was said and done, I believed that by moving into the organization of the Center for Hospice and Palliative Care, it would be a unique opportunity and would allow more patients to be cared for because we would have an organization that had all the components that we needed; an inpatient, a hospice license, and a homecare license. And we would be able to service many more patients, not only in the Children's Hospital, but we could look at expanding to the community hospitals, the other Catholic health system in Buffalo. We could start to look at other types of patients besides oncology and NICU and other diseases like neurogenerative disease and some of the chronic more complex patients. It was an opportunity for us to grow, and we did.

They ended up offering me the director position. The program ended up being moved and purchased under the Center for Hospice and Palliative Care. That transition allowed me to meet and work at a greater capacity on a national level and a state level. That's how I met Marcia Levetown because we were on a national taskforce together that looked at models. The New York State, at that time, was one of the five original states that received CMS [Centers of Medicare and Medicaid Services] funding for the project, PACC [Program of All-Inclusive Care for Children], which was Children's Hospital International's version of a waiver demonstration model project to show that this model worked.

My stipulation in going under the Children's Hospice and Palliative Care and the ideal model for us is that we had one team. So, the patients had one team of nurses, social workers, child life specialists. I brought all of that team with me—bereavement support. We had access to fundraising specific for children. Our program grew from 10 to 12 patients. In 1997, we transferred over to that organization with 10 patients on service and a year and a half later we had 50. We were now doing consults and seeing patients in the Catholic health system, the Children's Hospital, at the cancer center. That eventually grew to 80. In the middle of that is when we did the demonstration models. We internationally helped with some unique and innovative program development. We were making it work.

When I left Buffalo, New York, it was at a time when I had already been with Hospice Buffalo for 12 years. The program was going great. We had

just received a new state waiver—the money from CMS dried up, but the states were doing their own waivers. So, we created a palliative care waiver in New York State where, if you became certified in palliative care education and hospice and you could prove that you put your staff through a curriculum like ELNEC [End of Life Nursing Educational Consortium], because that's when—I mean I was on the ground with trying to develop the curricula for all of those palliative care programs at NHPCO [National Hospice and Palliative Care Organization] and ELNEC and stuff.

Anyway, that's when I think the movement really started to look at—because Buffalo wasn't unique. There were other pockets of programs like Marcia in Texas in Galveston with her Butterfly Program and another program in Atlanta that were, really, doing the same work. It was around that time that we all got together and started sharing information. You had groups that were really working together across the United States to make a meaningful change. I did work for about 10 years for NHPCO by chairing their pediatric committee, which I worked at with Marcia and many other colleagues in the country. I chaired the group to do the original pediatric standards for hospice and palliative care and it kind of took off from there.

[00:18:22]

***Bryan Sisk**:* So, early on, this was about probably the early to mid-90s when this really started taking off when Essential Care was purchased. Is that right?

Susan Huff: Yes.

***Bryan Sisk**:* So, earlier on in the late 80s, early 90s, palliative care was really non existant at that time. But even pain management as a field was still pretty early and pretty young and wasn't an official specialty. So, who did you learn from?

Susan Huff: I learned from Russell Portenoy, Kathy Foley and Nessa Coyle. There was a really innovative group at Memorial Sloan Kettering. They, along with Ellen Battista, she's a nurse practitioner that still practices in pain management in Buffalo. We had a multi-disciplinary pain service as Roswell in the late 80s that was just phenomenal. We had a psychologist, we had a psychiatrist, we had a nurse practitioner, physicians, and we used to do multi-disciplinary rounds on patients. So, we learned early on, we went and learned from Russell Portenoy. I'm so very sorry that I am

blocking the woman physician that was in charge of everything. Nessa was the—

[00:19:51]

***Bryan Sisk**:* At Sloan? Was it Kathy Foley?

Susan Huff: Yes, Kathy Foley. Sorry. So, they were also on our New York state cancer and pain initiative as we were meeting as a group and forming that. We used to hold conferences in Albany to train physicians on pain management. So, that was really who I learned from was that group from Memorial.

[00:20:15]

***Bryan Sisk**:* One thing I'm interested in digging into a little more deeply is this link that you formed between the pain management and palliative care. From talking to other people that are both pain specialists and then also palliative care specialists, it sounds like in a lot of places, these were largely parallel paths that didn't have a lot of crossover. So, what was your experience with being in the pain world and in this burgeoning palliative care world?

Susan Huff: For me, it was just a perfect fit. I was able to see adults and young adults when I was on the pain team as well as children. It was actually harder for me to see young adults than it was pediatric patients. We recognized that you needed that unique specialty and we were able to identify patients that really wanted to be at home. So, I was always a big proponent of the hospice philosophy of care, how you really needed to address all the different dimensions. I had the unique experience of having relationships with elderly people, people that were young like me, newly married and had children, and then taking care of adolescents, and then also infants and children. It was just, I always thought that it was a perfect fit. I know that the way the specialty forms. In many cases, the reimbursement is really what drives everything. That's why, in the early 90s when we formed the pediatric pain service, it was so new to everybody back then. It was important at that time for anesthesia to be involved, because you weren't making any money on the chronic patients that needed a lot of your resources. It was still the post-op anesthesia and the interventions that you were doing. I had an experience at Roswell with Dr. John Zoel was a neurologist that was—my God, when I worked with him, I think he was still doing surgery at 85. He was just an amazing technician. He would teach me and I was doing trigger point injections as a nurse. I would watch him do stellate ganglion blocks.

Mark Lema was another anesthesiologist who ended up to be a leader in the field of pain management along with Oscar de Leon. He was a resident when I worked with him. Oscar I think, runs the program at Roswell now. Back then in the late 80s, we were working with cancer patients and tunneling epidural catheters. These young adults were allowed to go to Hawaii on their vacations and take a pain pump with them or have their pain relieved in using regional approaches that were doing intrapleural blocks for patients that had advanced disease in their lungs and in their lung cavities and putting intrapleural pumps in with pain management and bringing that into the home environment. They had never heard about taking care of an epidural at home. I created policies and I went out to the home and I taught the nurses. And before you knew it, yep, we were taking care of epidurals at home. So, I know a lot of programs later on like the one in Minnesota with Stefan. When he came into the picture and came to the United States, when they formed their palliative care program in Minnesota, they did it in conjunction with their paying patients because it was a fit. It was a way to see patients and identify that they had pain needs, but they also had palliative care needs. They had needs that were eventually going to lead to end of life. It was important to take care of them early on. Sustainability is the challenge and even still today, it's the sustainability.

Eventually, the concurrent care law that ended up happening in the 2000s that exists right now for Medicaid patients, it still isn't the answer to everything. Right now, hospices are having a very difficult time getting things covered with the chronic complex, especially respiratory patients. They're still going broke because there's not a good mechanism for the long-term chronic patients that want services. Not only need services, but they want wrap around services.

[00:25:34]
***Bryan Sisk**:* I'd like to take a second and look back at the earlier 80s when you were doing your nursing work in pediatric oncology. What do you think were the biggest challenges in caring for kids that were suffering from serious illnesses at that time?

Susan Huff: It was important to recognize and be able to assess their pain needs. It was also important to be able to meet their psychosocial and family needs when they were dying in the hospital. Then the other amazing piece of it was the experiences that I've had with patients during their end stages,

being in their presence at the bedside, but also in their home. I mean I have amazing stories of parents who—I've gone into the home and took care of them when I was bringing medicine from the hospital just into the home. Those parents went on to do amazing things for children like this with foundations and things. They just never forget it. I could probably write a book about my experiences of taking care of children and being at their side when they died, just observation of relationships.

With the care team, the difference between physicians who really embraced it and wanted to have discussions and be open. I've had great, wonderful experiences teaching oncologists how to have the conversation with patients and how to be open and how to take the risk. All the things that we teach right now about taking the risk with conversation—we were doing all of that and trying to make sure that children had a voice and that their wishes were honored in how and what they wanted to do, those kinds of things. Those are the things that when I teach pain management or I teach courses on palliative care now, I try to bring all those experiences in what it's really like. I mean it's so different when you're talking about the different age groups. Taking care and working with adolescents is very different than a 10-year-old or a 13-year-old or a 3-year-old or a 6-year-old. It's just—I don't know. I think the communication and the ability to be there and be a presence was important.

The other piece that we had that was phenomenal, which is really important, is the support for the staff. So what was really cool about Roswell is that one day a week, we had a psychologist who was part of the team and saw patients as well. We had pysch rounds—we just called them rounds. Everybody sat in the backroom and we just talked about what was going on with our patients, what it was like to take care of kids that were our own kids' ages, what was the challenge, how it was affecting us, what was a good day, what was a bad day. We had that support. That was a really important aspect of the care that we had. I mean all my experiences—I think it's 42 years I've been in this. Hands down, my oncology training and experience when I graduated in 1982 working at Roswell for those first 10 years, that was like the foundation that helped me have the confidence and the interest to make changes for children later on. It was just a wonderful team experience.

[00:30:13]

Bryan Sisk: So from your perspective, what was the spark that really drove the development of pediatric palliative care as its own specialty?

Susan Huff: Parents wanting, and the fact that hospice was not going to budge on certain things, and parents saying that they wanted something different. When we could make a death better because of the way we were able to continue therapies and give medication by infusion. It was a while before you—I mean I even did original studies on MS Contin [Morphine Sulfate Controlled Release] and stuff. So, I mean by the time fentanyl patch came in and all the longer-acting meds, that was great. But before that, we really had to use infusion, continuous infusion. We would give continuous infusion with Narcan when kids were having itching. We were doing all sorts of different things. But parents were the drivers because I just—I didn't think it was fair that people had to stay in the hospital to receive certain things when all of it should be available at home. I always thought it was very important that parents had choices. Just because we had a system that worked for adults, that didn't work for pediatrics. I felt like it was really important that people understood why it was different and why we needed to create models that were suited for children.

[00:31:58]

Bryan Sisk: What do you think were the biggest challenges to the development as a specialty as this field started to grow?

Susan Huff: I think everybody was passionate about it. The biggest challenges along the way were going and making effective change from a legislative standpoint. Like it always comes down to money. You can't not rely on foundation and philanthropic support for everything. When it came right down to it, the bigger programs were able to do that just because they had these bigger foundations of adult programs that were able to fund them. From an equity standpoint, I felt like it was really important that we'd be able to draw in smaller places as well.

So, one of the things that we did when I was in Buffalo is we had more and more kids from the outer counties and different parts of western New York and the southern areas that has these smaller hospices. So, I created this kit where I started sharing all of our paperwork with them and our assessments. Then created this kind of consulting team from our team that said, "You can take of this patient. Here's all the tools that you need, and we'll be on call for you to help you with when you have questions or what

to do." So, that was a barrier. When we were home and we had parents home, and when things felt right, we did it.

I know that even because we were operating Essential Care out of a home health and I had a good physician. I think that was a barrier in the beginning. Afterwards, getting physician interest and find someone who was compassionate about it, was not hard. I think that was also very important, I have to say, in the development, is we found early on that you really did need a physician champion. So, that, I would say, really helped along the way. Yes. I mean even though this was a lot of nurse-run things, ideas and processes, you had to have a physician champion. I mean I could've never done the stuff we did early on when we didn't have home care programs and we were taking meds if I didn't have a physician who trusted us and who signed the order to say, "Okay. Great. Go take that." I mean, at that time, you had a medicine cabinet that we walked in and you could take Tylenol out of and drugs and didn't have a Pyxis and all that other stuff. So, that's why it was easy. But we always had physician support. They were willing to learn and willing to listen. I think it's because they saw the benefits of families being satisfied and we demonstrated that. We did surveys and we did pre and post to demonstrate that families were appreciative and the death was good. We always had physician champions. I think the biggest barrier, and it still exists, is the fact that there's these pockets of children that fall through the cracks. Funding is still a consistent issue because things aren't cheap. Not everybody, I think, needs all of the resources or the exact same services either.

[00:35:58]
***Bryan Sisk**:* How much do you think the adult hospice movement affected the development of pediatric palliative care and pediatric hospice?

Susan Huff: I don't think of it in that way. Honestly, I've had more people in leadership of hospice with the growth of the pediatric palliative care movement influence the growth of the adult palliative care movement more. They saw how we were providing services up front much more than they were ever with adults and that's where they got it. So, in a lot of ways, some of the hospice leaders—have you talked to anybody that was a person who was an administrative leader from the ground up in this movement?

[00:36:50]
***Bryan Sisk**:* I've talked to Ann Armstrong-Dailey. I've talked to Stephen Connor.

Susan Huff: Did you talk to Don Schumacher?

Bryan Sisk: No, I have not. That's a name I'll have to write down.

Susan Huff: Yes, Don—I mean Steve can give you background from a lot of places but not like Don Schumacher can. Steve worked for Don Schumacher. Don was the CEO of Buffalo Hospice in the early 90s when they made all the innovative changes for adults and peds. Then he went on to be the CEO of the National Hospice and Palliative Care Organization for 20 years. He recently retired in the last few years. So, he was very involved in a way parallel to Ann Armstrong-Dailey that made huge changes in palliative care for children alongside hospice. He did a lot of the things that in a unique way complimented what Ann has done but, in a lot of respects, far succeeded in different ways, much more than Ann was able to do from an international perspective in the United States. So, I would definitely suggest that if you have time, that you include Don Schumacher in interviews. I can send you his contact information.

[00:38:26]
Bryan Sisk: That would be wonderful. Another question I have relates on the concept of seamless care. So, what have the relationships been between in-patient units versus hospitals, outreach in the community, versus community hospices? What has been that relationship between all of those different entities in the care of these children? How as that contributed or not, to this concept of seamless care for these kids?

Susan Huff: Well, I think it's of utmost importance to develop trust in that relationship and it’s vital no matter what community you're in. I've always said that Essential Care might have been one of the first couple programs that was developed in the United States. St. Mary's Bayside by the way, in New York City—I don't know if you've talked to anybody from them. But they had a palliative care system in-patient in the late 70s. I mean they were doing a lot of innovative palliative care work in their children's hospital before.

Anyway, I've always said that even though Essential Care was such a wonderful model. By the way, even when I left Buffalo, I'm very proud to say that they're up 80 to 100 patients right now. They're still thriving and growing in western New York in serving patients and families. So, it has a model that has been able to show sustainability. It's changed a lot over the years but the mission of caring for those children in the way that you need

all of those disciplines available to the family has survived. So, you could take a model and a program and plop it into a different city and community, but you can't run it the same way, but you have to have the same foundation. And in that foundation is the trust and respect of providers. So, you have to have, in order to provide that seamless care. An organization that's run out of a community, needs to have the respect and trust of the primary specialists and the pediatricians that are providing the care.

With most of these children that have chronic complex needs, or even oncology patients who get better. I mean 60% of our patients in oncology graduated, but 50% of those that ended up graduating out of Essential Care ended up coming back because they went into end stage and died. So, we showed that we were still taking care of the right population, even though 75% of our referrals for our oncology patients were when they were first diagnosed. It was amazing. We were showing them a way to navigate and adapt to the new normal when their child was diagnosed. When they didn't need the services, they didn't need the services. Then we stayed in touch with them through an outreach program. Then when they relapsed or had something else happen catastrophically, we had already developed trust and rapport and we were able to get right back in and follow them through end stage.

Having relationships with specialists is really important and gaining the trust. That's the only way everywhere I've been I've been able to build the program, even at Hopkins. Very different situation when I arrived in Baltimore. Unique community and Hopkins has its own unique challenges. The only way I was able to build a program was to be integrated as a community provider, even though I was within the health system.

When I first came to Hopkins, our referrals in that home care company, the majority of the referrals were from the University of Maryland. They weren't even from Hopkins Children's Center, and we were their own program. So, my first challenge was to integrate into that community, to gain trust, to be present, to educate, to show what you can do, to make sure you say what you can do. To communicate the right way with the physicians. To make sure that there's follow up and develop that trust. Now, it's totally the opposite. Now, we've expanded and we're now the

preferred provider for Children's National in D.C. and we service all community hospitals and programs throughout the Maryland region. It's grown because that continuum of care is vital. You have to have a presence and be available to the patients when they're in the hospital and then continue that work as a community provider. There has to be communication with the primary pediatrician as well. It's vital.

[00:44:00]

***Bryan Sisk**:* We've got about, looks like maybe six or seven minutes left. I've got three questions that I was hoping to get through. First, where do you think this field is the strongest right now? What's the best thing going in this field?

Susan Huff: Oh, my God. I think the most phenomenal thing over the last several years for people that want to be in this field is the lip service. [*laughs*] The fact that you, anywhere in the world have a question about a patient and you get an immediate response from millions of experts and I'm being—obviously, not millions, but you get my drift. It just, because those of us who started in this field 25, 30 years ago, we were blind. We were like shooting by the seat of our pants and calling each other. I remember trying to get a hold of Neil Schechter and trying to get him on the phone to ask him a pediatric pain question years and years ago and having to wait. So, it's just really, really interesting that there's this community now that exists all over the place related to pediatric palliative care. You have so many experts that are willing to lend their expertise to that table. So, I think from a community standpoint, it's strong because so many people know about it and are interested in committing to it, and that's the biggest strength.

[00:45:34]

***Bryan Sisk**:* What do you think is the area that needs most to grow?

Susan Huff: I wish that there was more data on the longevity of the field. I really regret not—I did a lot of work and helped a lot of other people publish but didn't do a lot of initial publishing work. I'm just starting with a group at Hopkins about publishing work now. I think what's needed is to be able to follow families and to understand the impact from a long-term standpoint on the care that is provided in palliative care. Then the survivors of the children and the family and how that impacts. We don't know how it impacts really. It's really expensive care. It's good care. I just think we need to learn more about it. I think there's a lot of research that still needs to be done in the outcomes. I think there's a lot of—well, I'll just leave it at that because there's so many other questions, but yes, especially outcomes research.

[00:47:12]

***Bryan Sisk**:* Well, lastly, I would love for you to just dream aloud. If budget and politics and reimbursement and turf and all of these things, if none of those were obstacles, what would you ideally want care for these children to look like in another 10 years?

Susan Huff: I would love for there not to be this array of, "This is a hospice benefit, this is a home care benefit." I understand the reasons why we have to have the criteria for things. But I'd like to have the ability for people of all ages to have choices in a seamless amount of care or seamless choices in care and access. And I'm not referring to the way that people say, "Well, you go to Canada or you go to Europe and you have socialism, and everybody gets everything." That's not true and it's not the answer. I mean you have—I can name you 10 physicians right now that have worked in this field for 20 years and lived in those countries, including Canada, but they moved to the United States because they could live here better and practice better and the medicine was better. I think we need, as a country, to look at it differently. We need—I don't have the answer, but I would love in 10 years for there not to be these silos. Someone is getting hospice care now. Someone is getting this care now. It would be regarded as more of a life experience in wherever they are with their health, their disease, and their family at the present time, I guess.

[00:49:35]

***Bryan Sisk**:* Great.

Susan Huff: I don't know. Probably it doesn't make much sense to you but—and I know getting rid of the hospice benefit isn't the answer. It was amazing and it's a wonderful philosophy and it's been a huge amazing benefit for others. But it's also created these pockets where there's these gaps in care of people who need things that aren't getting them. We do things in this country because we can get paid for them. I know that there has to be a balance between getting paid for things and looking at things. I just think that's why I think there's more outcomes research that's done. I'd love to be able to identify in a better way, the families and children that really present at high risk to certain types of needs, too. That would be interesting. That doesn't really exist now, either.

[End of Audio]